410* How we managed to improve a professional attitude in the nursing team to deal with topics of sexuality, fertility and reproduction in relation to CF patients

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Background: During the annual European Cystic Fibrosis Congress in 2007 we presented the results of a questionnaire about dealing with topics of sexuality and fertility in relation to CF patients. The questionnaire was offered to the nursing staff of the Cystic-Fibrosis department of the University Medical Centre Utrecht in the Netherlands. The outcome showed the nursing staff was insufficient equipped to deal with these issues. It was evident the nursing staff needed knowledge and a model to help them bring up sexuality and fertility issues with the CF patient.
Method: The poster mentioning the outcome was rewarded with the third prize during the annual European Cystic Fibrosis Congress in 2007. The money we won was used to hire a sexual therapist to lead a workshop. In the fall of 2007 the entire nursing team attended the programme.
Aim: To develop a professional approach to handle these issues.
Together we developed a manual. This manual was intended to be helpful to the nursing staff in order to develop a professional approach concerning sexuality, fertility and reproduction in relation to CF patients.
In the fall of 2008 we offered the same questionnaire to the entire nursing staff. There was a response of 70% which was comparable to 2006. In the 2006 inquiry only 10% of respondents stated that they initiated such a discussion. In 2008 50% of the respondents did initiate a conversation about these topics.
Conclusion: There was an improvement of 40% in the respondents to deal with issues concerning sexuality, fertility and reproduction compared to 2006. The outcome showed we are improving but we need to remain active in coaching the nursing staff concerning these topics.

411 Pregnancy and CF: Differing perspectives of patients and caregivers

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Background: Cross-sectional studies have shown that pregnancy/normal term delivery is safe for women with CF, but may be a risk factor for women with advanced lung disease. The potential hazards may trigger a moral conflict between the caregiver's advice against pregnancy and the patient's desire for motherhood.
Aim: 1. To compare the views of caregivers and women with CF with respect to pregnancy. 2. To analyze the relationship between the severity of the disease and the decision to become pregnant.
Methods: The survey included all female patients over age 18 in the Israel CF registry and all 6 CF centers in Israel. Anonymous questionnaires incorporated demography, disease severity, personal opinion on pregnancy, open questions on anxiety during/after pregnancy.
Results: 36 patients (70% of all adult females with CF, mean age 27.5 yrs, FEV1 57.5%, PI 71%, CFRD 41%) and 36 caregivers (average age 43.3 yrs, 11 male/25 female) from all CF centers in Israel responded to the questionnaire.16 CF patients gave birth to 32 children. Caregivers, more than patients, perceived severity of disease to be the limiting factor in pregnancy. Both caregivers and patients agreed that high pulmonary functions (FEV1 > 90%) are no obstacle to pregnancy, for moderate pulmonary functions (FEV1 < 50%) caregivers more than patients advise to refrain from pregnancies. In contrast to patients, caregivers prefer the wellbeing of the patient over the health of the fetus. A relationship between religious observance of the patient and objection to abort were noted. Treatment compliance during pregnancy was higher than predicted by caregivers.
Conclusions: A gap in the perception of pregnancy was observed between caregivers and CF patients. Pregnancy counseling should therefore be incorporated into the treatment plans for adult women at CF centers.

412 A tool to facilitate transition to adult care for young people with cystic fibrosis

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Background: Maintaining a programme of care to facilitate transition to adult services is challenging. We have developed a Transitional Care Programme Record (TCPR) as a tool to facilitate this process and have completed a 5 year review.
Method: A retrospective case note review of all patients over 13 (when TCPR starts) attending Alder Hey, including young people that transferred to the adult clinic over the past five years.
Results: 41/45 (91%) patients had a TCPR. In 14/41, a revised version of the record was used (modified following previous review). In 28 patients who have transferred to adult care, use of the revised version was associated with a higher rate of completion (75% versus 35% with the original). It was clear that the record facilitated team communication and ensured that a clear flow of information was given to the young people.
Discussion: This audit suggests that the TCPR can be an aid to ensuring that each patient benefits from the Transitional care Programme that we have established. This tool continues to develop through an iterative process with the aim of ensuring that all patients have a TCPR and that it is used effectively to aid a smooth transition from paediatric care.

413 Transition from paediatric to adult: experience of a cystic fibrosis care center

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Background and Objectives: Whereas patients with cystic fibrosis (CF) improve continuously their life expectancy, guidelines for transition to adult services have not been clearly determined yet. The aim of this study was to analyse the management of this transition in the CF care centre of Angers, France.
Patients and Methods: From their medical file, we have analysed the transfer of 22 patients with cystic fibrosis from paediatric to adult care. Perception of patients and care givers regarding this transition was evaluated using anonymous questionnaires.
Results: The initial objective was to transfer patients around 18 years offering them 3 or 4 consultations with paediatrician and adult lung specialist, both together. Median age of transfer was 22 and median duration was 9 months. Half of patients had only one joint transfer consultation during transition. Age of 18 and maturity were the most common criteria mentioned for transfer. All highlighted difficulty to leave an attaching paediatric team and its familiar environment. Care givers described the transfer as a success whereas half of patients were unsatisfied of it, indicating, as doctors and nurses, that transition was too short without enough joint consultations.
Conclusions: This study shows this period as a major life event for the patient with CF. Transition process has to be organised with him and independent behaviours have to be encouraged. Adults and paediatric teams need to cooperate. Based on this experience and former medical data, we suggest a transition program for patients with CF.